

Study of the Associated Risks of Stillbirth - SOARS



The Study of Associated Risks of Stillbirth (SOARS) is a pilot surveillance project of the Utah Department of Health (Maternal and Infant Health Program) and the Centers for Disease Control and Prevention (CDC). Through the project, data is collected from women who have recently delivered a stillborn infant by way of a mailed survey with telephone follow-up. The survey is designed to collect information on maternal experiences and health behaviors before, during, and after pregnancy. The methods used for data collection are based on the well-established methods used by the Pregnancy

Risk Assessment Monitoring System (PRAMS) for collecting data from women who have delivered a live infant. The Utah Department of Health has been collecting PRAMS data since 1999.

This pilot project was funded for three years (2016-2019) with a projected timeline of one year for implementation, one year of data collection, and one year for data analysis.

Activities completed during the implementation phase included establishment of an advisory committee (comprised of medical experts, parents, and others interested in stillbirth prevention), development of questionnaire and supporting materials, testing of questions, Institutional Review Board approval, protocol and database development, and grief support training. Due to additional time needed for question development and IRB approval, the implementation phase was extended to 2 years.

The first year of data collection will be completed by the middle of October 2019. The following are process results as of August:

- Number of surveys mailed: 262
- Number of surveys completed: Mail: 146, Phone: 15 (response rate: 58.7%)
- Number of hard refusals: 6
- Number of women with negative feedback: 1

Plans for analysis of SOARS data include the following:

- Improvement of support processes for families experiencing stillbirth
- Enhance the understanding of maternal experiences and behaviors and their relationship to stillbirth
- Hospital/physician practices related to understanding causes of stillbirth

Additionally, findings from assessment of the surveillance process will be shared with the CDC, other state PRAMS programs, and interested medical community for use in development of stillbirth surveillance programs.

Comments from parents:

"It is my hope that my participation with this survey will help provide answers to the reasons why this happens... Thank you for this program and helping to find answers!"

"We're so grateful you're taking these surveys because we don't want anyone else (especially those without a proper support system) to experience this. I hope I've been helpful"

"Go save these babies! Data is powerful."